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Professional Practice

Advancing Nutrition and Dietetics Practice: **Dealing With Ethical Issues of Nutrition and Hydration**

THICAL ISSUES OF NUTRITION and hydration involve decision making for individuals and their health care team about the delivery of nutrients through tubes, both enteral and parenteral routes. The goal is to provide this method of nutrient administration only if acceptable to individuals based on their wishes.

Registered dietitian nutritionists (RDNs) are knowledgeable in all aspects of nutrition and can work collaboratively as part of an interprofessional health care team to make recommendations on oral feeding, including providing, withdrawing, or withholding artificial nutrition and hydration (ANH), and can serve as active members of Bioethics Committees. The nutrition and dietetics technician, registered (NDTR) works under the supervision of the RDN.

This article provides RDNs tools for understanding their role in dealing with ethical issues of nutrition and hydration and how to create a proactive, integrated, systematic process to achieve sustainable clinical practice changes in ethical issues of ANH based on evidence, individual values, and professional judgment.

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CODE OF ETHICS

The Code of Ethics for the Nutrition and Dietetics Profession indicates that when providing services, the RDN and NDTR adhere to the core values of individual focus, integrity, innovation, social responsibility, and diversity. Decisions are science based, with consideration of the individual situation and professional judgment. The Code's primary goal is the protection of the individuals. groups. organizations. communities, or populations with whom the practitioner works and interacts. RDNs and NDTRs support and promote high standards of professional practice.1

Based on the Code of Ethics, the RDN can participate in ethical decisions for feeding, including providing, withholding, or withdrawing ANH. These decisions can include the RDN supported by evidenced-based practices, involving an interprofessional health care team approach, and utilizing patient-centered and family-centered care.2

PATIENT'S RIGHT IN SELF-**DETERMINATION**

The 1990 Patient Self-Determination Act encourages everyone to decide about the types and extent of medical care they want to accept or refuse if they become unable to make those decisions due to illness. The Patient Self-Determination Act requires all health care agencies to recognize the living will and durable power of attorney for health care (DPAHC).³ The DPAHC is also called a medical advance directive.

Individuals deemed competent to make decisions would receive information on all nutrition options (oral, feeding assistance, enteral, or parenteral). Advance directives such as living wills are legal documents that allow individuals to convey their decisions

about end-of-life (EOL) care to family, friends, and health care professionals. Living wills stipulate the type of medical and health care the individual desires to sustain life, such as tube feedings. The DPAHC identifies the individual's surrogate, who would make health care decisions when the individual is not capable. If they are considered competent, individuals may change the content of their advance directives. Advance directives can be updated periodically, because the perception about acceptable quality of life (QOL) may change over time. Individuals with a serious illness or advanced frailty near the EOL or their representative and the physician can complete a Physician Orders for Life-Sustaining Therapies. Nutrition practitioners can utilize their decision making based on ethical positions of professional organizations and the institution's policies on administering and withdrawing ANH, prioritizing the individual's or designee's by DPAHC's desires.

COLLABORATIVE ETHICAL DELIBERATION ELEMENTS

RDNs, as members of the interprofessional health care team, may have sufficient knowledge of clinical nutrition, moral reasoning, health care law, and institutional policy to assist the individual or surrogate make informed decisions. These teams are composed of members from different professions and occupations with varied and specialized knowledge and skills. Knowledge, skills, attitude, decisionmaker considerations, and bioethical principles are ethical deliberation elements that provide the framework for working in collaboration to present recommendations to individuals.

Figure 1 presents the 4 bioethical principles that are internationally recognized. These principles are interrelated and aid in decision making.4

Autonomy	Respect for the autonomy of the individual is a very strong value in American culture. Competent adults with full knowledge and understanding of the information necessary to make a decision should be free to make their own choices without undue influence. There is a limit to freedom, but that limit has to be defined with each situation and ought to strongly favor the individual.
Beneficence	Taking action for the benefit of the individual is the goal of clinical decision making; whatsoever action is taken should be the most beneficial for the individual.
Nonmaleficence	e This word means "do no harm." This is a guide to action in clinical medicine. It is the warning to take care that whatever is done to help does not also hurt the individual. Basically, the balance of help and hurt must favor helping the individual.
Justice	Distributive justice is more difficult to apply in clinical medicine. Justice as "fairness" is the main formula used in clinical decision making. The moral action is the fair action that treats each person as equal to all similar persons in similar circumstances.

Figure 1. Bioethical principles.⁶

Figure 2 identifies important concepts incorporating the elements of collaborative, ethical deliberation.

COLLABORATIVE ETHICAL DELIBERATION PROCESS

Roles and Responsibilities of RDNs

RDNs and NDTRs, working under the supervision of the RDN, may forgo completing a nutrition assessment when the patient is deemed at EOL and should provide evidence regarding risks and benefits of ANH. The RDN is ultimately responsible for working with the team and individual or designee in the nutritional care of individuals in the health care setting considering ANH. Ethical deliberation would occur when conflicts and dilemmas in treatment decisions arise. It is the responsibility of each health care professional to have sufficient experience with clinical ethics to participate in or to facilitate discussion. The RDN provides education that can assist other clinicians with intricate and complex issues of ANH. The education/discussion will involve the family/surrogate if the individual is not able to be involved. A Bioethics Committee, including an RDN as a member, is highly

valuable.⁵ The RDNs often have specific knowledge regarding the individual's preference because they discuss feeding issues with the individual and family.

The RDN may assume the responsibility of communicating with the team so that feeding issues are deliberated in such a way to consider all appropriate options, rather than thinking that any strategy of feeding or not feeding is obligatory. For example, the conclusion may appear that an enteral feeding tube is the only option, when careful oral feeding assistance may be an appropriate option for adequate nutrition.

Nutrition practitioners should refrain from personal bias and be mindful of patient autonomy. Moral tension can be reduced but not resolved if, during the ethical deliberation, the dissenting RDN respectfully presents his or her personal and professional view. Otherwise, the RDN may recuse himself or herself from the case and find an alternate RDN, who will be able to participate in the case.

Aspects of Withdrawal of ANH

Essentially, there is no ethical difference between withholding and withdrawing life-sustaining therapies,

including ANH. However, decisions to withdraw ANH rather than withhold the intervention may cause more psychological and emotional responses for clinicians, patients, and their family members. The withdrawal of ANH does not preclude other care for the individual. The care focus is on what the individual wants in the present clinical situation.

ANH DECISIONS AND GOALS

When there is a reasonable life expectancy or QOL, ANH-in this case referred to as nutrition support—using the enteral or parenteral route may support and improve quality and quantity of life. This improvement may occur in patients with short bowel syndrome, cancer, head and neck cancer, acute stroke with dysphagia, neuromuscular dystrophy syndromes, and gastric decompression.^{7,8} ANH for older adults may be appropriate when a return to prior functioning is anticipated, such as in individuals who have had surgery, trauma, a stroke, or burns and expect to recover.9

The American Society for Parenteral and Enteral Nutrition (ASPEN) and Academy of Nutrition and Dietetics revised 2014 standards of practice and standards of professional performance for RDNs (competent, proficient, and expert) in nutrition support incorporated a standard involving QOL and individual perception on the intervention, cultural, ethnic, religious, and lifestyle factors and impact on life.¹⁰ The 2018 ASPEN Standards for Nutrition Support: Adult Hospitalized Patients provided a standard on nutrition therapy at EOL. During the EOL setting, the patient, patient's family member(s), or surrogate decision maker makes the decision on acceptance or refusal of the medical and nutritional therapies based on informed opinion, with the caveat that the clinician is not obliged to provide futile nutrition support therapy and hydration to a patient in the EOL situation.¹¹ ASPEN developed a position paper on ethics to provide a critical summary of the major ethical and legal issues related to the ANH, which may guide practitioners confronted with dilemmas.12

- The individual's expressed desire for extent of medical care is a primary guide for determining the level of nutrition intervention.
- 2. The decision to forgo ANH^a should be weighed carefully because such a decision may be difficult or impossible to reverse nutrient deficits in a period of days or weeks.
- 3. The expected benefits, in contrast to the potential burdens, of nonoral feeding must be evaluated by the health care team and discussed with the person. The focus of care should include the individual's physical and psychological comfort
- 4. ANHs is a medical treatment.
- 5. Consider whether or not nutrition, either oral or through a tube, will improve the individual's preferred quality of life during the end-of-life period.
- 6. Consider whether or not nutrition, either oral or through a tube, can be expected to provide the person with emotional comfort, decrease anxiety about disease cachexia, improve self-esteem with cosmetic benefits, improve interpersonal relationships, or relieve fear or abandonment.
- 7. If death is imminent and feeding will not alter the condition, consider whether or not nutrition through tubes will be burdensome, creating discomfort for the individual.
- 8. When oral intake is appropriate:
 - Oral feeding should be advocated whenever possible, based on an individual's desire. Food and control of food intake may give comfort, pleasure, and a sense of autonomy and dignity. The most important priority is to provide food according to the individual's wishes.
 - b. Efforts should be made to enhance the person's physical and emotional enjoyment of food by encouraging staff and family assistance in feeding the individual, as needed.
 - Nutrition supplements, including commercial products and other alternatives, may be used to encourage intake and ameliorate symptoms associated with hunger, thirst, or malnutrition, if these occur.
 - The therapeutic rationale of diet prescriptions for an individual should be reevaluated. Dietary restrictions should be liberalized. Coordination of medication or medication schedules with the diet should be discussed with the physician, with the objective of maximizing food choices and intake by the person.
 - The person's right to self-determination must be considered in determining whether to allow the individual to consume foods that are not generally permitted within the diet prescription.
 - f. Suboptimal oral feedings may be more appropriate than burdensome ANH.
- When enteral tube feeding or parenteral feeding is being considered:
 - a. The informed individual's preference for the level of nutrition intervention is primary. The person or designated surrogate decision maker should be advised on how to accomplish whatever feeding is desired.
 - b. When palliative care is the agreed goal, consideration of use or discontinuation of ANH should be part of the discernment process, based on the informed person's wishes, including benefit and risk burden.
 - Feeding may not be desirable if death is expected within hours or a few days and the effects of partial dehydration or the withdrawal of ANH will not adversely alter the individual's comfort.
 - Health care facilities should provide and distribute written protocols for the provision of and termination of enteral tube feedings and parenteral feedings. The protocols should be reviewed periodically, and revised if necessary, by the interprofessional health care team. Legal and ethical counsel, as needed, should be routinely sought during the development and interpretation of the guidelines. The health care facilities' ethics committee, if available, should assist in establishing and implementing defined, written guidelines for a nutrition support policy. The registered dietitian should be a contributing member of the committee.
 - Conflict within the family or among stakeholders can be resolved by referring to an ethics committee or consultant if available within the institution.
 - f. The potential benefits versus burdens of enteral tube feeding or parenteral feeding should be weighed on the basis of specific facts concerning the individual's medical and mental status, as well as on the facility's options and limitations.
 - Health care facilities limitations that should be considered:
 - (1) Lack of staffing, limiting ability to manage and monitor feeding;
 - Financial limitations: (2)

(continued on next page)

Figure 2. Suggested ethical deliberations about nutrition and hydration.

- (3) If a feeding strategy is started in one site, it may have to be stopped when the individual is transferred to another site within the same facility or to another facility. This can lead to a sense of abandonment for the person.
- Either short- or long-term parenteral nutrition should be considered only when other routes are impossible or inadequate to meet the comfort needs of the person.
- 11. When the physician's diet order in the medical record documents the decision to administer or forgo ANH:
 - a. RDN^b should participate in the decision process.
 - b. If a decision is made that the RDN does not agree with, the RDN should first contact the ordering physician to discuss; then the RDN would discuss with the primary physician if the ordering physician was a consultant. The RDN should discuss with the individual's nurse and document in the medical record, indicating persons contacted and the outcome. If the RDN felt this was not resolved, the RDN should contact the facility's ethics mechanism (committee or consultant) and document in the medical record.
 - c. If the court has ordered feeding or no feeding and there is disagreement with the court's decision, appeal to the facility's ethics mechanism is appropriate.

 a ANH = artificial nutrition and hydration, also known as nutrition support (enteral tube feeding and parenteral nutrition).

Figure 2. (continued) Suggested ethical deliberations about nutrition and hydration.

HEALTH CARE GOALS BY CONDITIONS AND CIRCUMSTANCES

Advanced Dementia

Individuals with end-stage dementia typically lose interest in food/fluid, become too confused to focus on meals, and may refuse to eat by turning their heads away from food or clamping their mouths shut. A Cochrane Review found no evidence that enteral tube feeding provides any benefit for individuals with dementia in terms of survival time, mortality risk, QOL, nutritional parameters, physical function, or improvement or reduced incidence of pressure ulcers.¹³ Despite the research data and recommendations to forgo enteral tube feeding in advanced dementia, the practice continues.¹⁴

Researchers and experts support that careful hand-feeding is the recommended standard of care for older adults with advanced dementia.¹⁵ If family/caregivers request a tube feeding, a health care clinician can discuss the benefits and risks of the therapy. Consideration of the individual's prior wishes and recognition that tube feeding cannot stop the progression of dementia nor prevent imminent death should be shared with family caregivers.¹⁶ Change in clinical practice from placing long-term feeding tubes in patients with advanced dementia could be enhanced by the use of an algorithm for decision making or a checklist of appropriate indications for use before the placement of long-term enteral access devices.¹⁷

Disorders of Consciousness

The American Academy of Neurology in 2018¹⁸ published practice guidelines suggesting terminology changes and recommendations for care of individuals with altered degrees of consciousness. The recommendations include changing from vegetative state (VS) to unresponsive wakefulness syndrome, changing permanent VS to chronic VS, and using the term "minimally conscious state."

With various disorders of consciousness, withholding or withdrawal of treatment can be discussed throughout the hospitalization with family/surrogate decision maker, when appropriate. ANH is considered medical treatment. ANH can be withheld or withdrawn, if the surrogate withdraws consent, because the treatment fails to deliver the intended benefit or causes a disproportionate burden.¹⁹

Terminally III Individuals

Individuals with a terminal illness often described as an illness with a prognosis of death in 6 months may benefit from oral nutrition or hydration based on their current condition. Declining food and fluid intake and unintended weight loss are a natural part of the disease progression. Individuals with a terminal illness who select hospice services are generally not considered candidates for

ANH. Potential problems associated with enteral tube feeding include aspiration, diarrhea, overhydration, discomfort, and interference with personal dignity. As EOL approaches, individuals may not experience hunger or thirst. The absence of food and fluid intake may result in ketosis and a release of opioids in the brain, which may produce a sense of euphoria.²⁰

Literature suggests that the benefits of providing ANH in patients with cancer in the last days of life are limited and do not clearly outweigh the burdens.²¹

Decision Making in a Pandemic

In a pandemic, such as coronavirus disease 2019 (COVID-19), health care clinicians, therapies, procedures, and equipment may become scarce resources. Those limited resources force hard decisions. Ethical decision making requires determining the delivery of optimum health care to the right individual, in the right place, at the right time. Mostly the top criterion becomes the chance of survival.

In a pandemic, the health care infrastructure can be overwhelmed, resulting in rationing medical equipment and interventions. The COVID-19 pandemic resulted in increased demand and some instances of a shortage of personal protective equipment, hospital beds, intensive care unit (ICU) beds and supplies, and ventilators, along with the availability of the medical workforce, which became ill or quarantined.²² Emanuel

^bRDN = registered dietitian nutritionist.

- 1. Policy Statement: The interprofessional health care team provides ethically and medically appropriate ANH^a, based on published evidence-based guidelines and recommendations of recognized authorities. The focus of this policy is to translate these guidelines and recommendations into patient-centered clinical practice.
- 2. Important considerations may include components from following the organizations and other organizations as appropriate for the individual population:
 - a. Academy Nutrition and Dietetics
 - b. American Academy of Family Physicians Center
 - c. American Academy of Neurology
 - d. American Academy of Pediatrics Clinical Report
 - e. American College of Physicians Ethics Manual.
 - f. American Medical Association Policy on Provision of Life-Sustaining Medical Treatment dealing with nutrition
 - g. American Nurses Association
 - h. American Society for Parenteral and Enteral Nutrition Ethics Position Paper
- Procedure:
 - a. A collaborative effort by the interprofessional health care team determines the individual's wishes as expressed directly and/or by a designated surrogate health care decision maker when the individual is not able to express desires for health care treatments, which may be used for ethically appropriate ANH.
 - b. Written documentation, an advance directive designating surrogate decision maker and treatment preferences, in the individual's medical record is encouraged throughout the health care system to help in the decision process for ANH. Within the first 24 hours, the surrogate decision maker should be clarified, whether advance directive exists should be determined, and a copy should be placed on chart and reviewed by provider.
 - c. Clinical judgment based on a collaborative effort by the health care team including the individual/surrogate/family, in conjunction with published guidelines, should be used in the process to withhold or withdrawal ANH, including RDN^b involvement.
 - d. Family care conference is recommended for individuals in the ICU^c 5-7 days or less to address plan of care and QOL^d goals and to determine the decision maker if an advance directive is not on the chart to provide direction for treatment from the individual or an appropriate surrogate decision maker for ANH. Written documentation of family care conference discussion and decisions should be included in the medical record.
 - e. Palliative care team consult is recommended early in the process to assist with clarification of QOL goals and assist with family, including ANH. Individuals in the ICU \geq 3 days should be screened for support care needs by palliative care team members.
 - f. Bioethics committee consultation is recommended when there is a conflict in the process to withhold or withdrawal
- . References (sources used to develop policy and procedure) should be provided.
- 5. Approval: committee/approval date should be noted.

^aANH = artificial nutrition and hydration.

^bRDN = registered dietitian nutritionist.

^cICU = intensive care unit.

 $^{d}QOL = quality of life.$

Figure 3. Sample format for acute care ANH ethical decision-making policy and procedure.²⁶

et al²³ proposed 4 ethical values in a pandemic: maximizing the benefits achieved with limited resources, treating people equally, promoting and rewarding instrumental value (giving priority to those who can save others or to those who have saved others in the past), and giving priority to the worst off. These 4 proposed ethical values may be a matter of intense ethical debate.

Encouraging all individuals to include in an advance directive what

future QOL they would regard as acceptable and when they would refuse ventilators or other lifesustaining treatments would assist clinicians in the allocation of resources.

UNDERSTANDING CULTURAL VALUES AND RELIGIOUS DIVERSITY IN CLINICAL ETHICS

The understanding of cultural and religious diversity in clinical ethics is

essential to meet an individual's wishes best. This awareness provides the RDN the ability to tailor information for individuals, families, and sigpromote nificant others that understanding of life-sustaining treatments, which includes ANH. Various cultural values and religious diversity perspectives are not to be inclusive for everyone in that religious or cultural group. They are to facilitate the understanding of possible religious and cultural diversity. A literature review

Policy statement: The interdisciplinary team provides ethically and medically appropriate ANH^a based on published evidence and guidelines. Advance directive documents will be reviewed. Each individual will be evaluated prior to recommending enteral feeding. A variety of interventions will be attempted before ANH is considered.

Procedure:

- 1. The interdisciplinary team will contact the physician and RDN^b when the individual's ability to maintain appropriate nutrition parameters is impaired and/or nutritional status is declining.
- 2. The interdisciplinary team will review all previous assessment criteria: speech-language pathologist evaluations, testing and diagnosis of dysphagia, assisted feeding procedures, oral nutrition supplements and/or fortified foods offered, weight records, and food/fluid intake for past 3-5 days.
- 3. If oral nutrition and hydration cannot sustain adequate nutrition, the RDN will complete a comprehensive nutrition assessment. The RDN may recommend enteral nutrition if consistent with the individual's goals.
- 4. The physician will complete an evaluation of the individual's clinical condition.
- 5. The interdisciplinary team will discuss the risks and benefits of ANH with the individual and/or family/DPAHC^c. The meeting will include discussion of the individual's current medical condition, ability to tolerate ANH, and quality of life.
- 6. If the individual and/or family/DPAHC determine that ANH is appropriate, the team will request an order from the physician.
- 7. If ANH is declined by the individual and/or family/DPAHC, the physician will be notified.
- 8. Based on the physician's orders, the interdisciplinary team will discuss the provision of palliative and/or hospice care with individual and/or family/DPAHC. The person-centered plan of care and medical record will reflect the decisions, goals, and choices made by the individual and/or family/DPAHC. The plan will direct daily care to maintains the highest practical quality of life based on the individual's wishes.

^aANH = artificial nutrition and hydration.

^bRDN = registered dietitian nutritionist.

^cDPAHC = durable power of attorney for health care.

Figure 4. Sample guideline for ANH for long-term facility.

by Steinberg noted that an individual's religious and cultural beliefs heavily influenced their EOL decisions.²⁴ Some religions make a distinction between ordinary and extraordinary treatment or view pain as something an individual should endure.

INTEGRATING QOL GOAL SCREENING INTO RDN CLINICAL PRACTICE

QOL Goal Screening

Just as patient screening for nutrition risk occurs before recommending and implementing nutrition therapies, similarly, QOL goal screening by the health care team is crucial. This QOL screening involves checking the medical record by the health care team members, including the RDN, for an advance directive and Physician Orders for Life-Sustaining Therapies for information related to the individual's health care wishes for medical treatment options. Health-related QOL assigns values to the duration of life as modified by the impairments, functional states.

perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy. QOL is highly individual with high levels of variability between individuals. Nutrition, whether provided orally or through tubes, can provide a sense of caring for the individual/surrogate/family. However, it may become more difficult to withdraw after being initiated than to be withheld initially. 26

The Institute of Medicine defines patient-centered care as "respectful of and responsive to individual patient preferences, needs, and values" and care that ensures "that patient values guide all clinical decisions."²⁷ This definition emphasizes the importance of clinicians and individuals working together to produce the best outcomes possible, rather than a disease outcome-based paradigm.²⁸

Case Study During the COVID-19 Pandemic

An 83-year-old man was admitted to the ICU with deteriorating respiratory

status and a positive COVID-19 test. His condition required intubation with mechanical ventilation. No visitors were allowed in the hospital, including immediate family members, to reduce health care workers and other patients' exposure to COVID-19.

Although his wife was not able to be with him in the hospital, she had written out in advance his medical history and presentation of his current illness before he entered the emergency room. Over the previous 3 days, his food intake had declined due to his coughing and high fever. It was a struggle even to keep up his fluid intake during that period. The medical history revealed the man did not have any preexisting disease process, such as cardiac or respiratory disease or diabetes, that would have put him at increased risk for severe illness.

Additionally, his wife provided an advance directive, updated with a handwritten section by the patient to use if he required mechanical ventilation for an extended period without improvement during the COVID-19 pandemic. He would agree with a

future decision, if needed, to remove him from the ventilator and provide the opportunity to use the ventilator for another individual who might have a better chance of survival. The patient acknowledged that his death might then occur. This kind and selfless designation was to assist health care clinicians prioritize limited resources during a difficult and extraordinary period of health care delivery.

The RDN completed nutrition assessment, obtaining information from the patient's electronic medical record. Before the pandemic, ICU clinicians performed rounds daily on all patients for collaboration of health care needs in real time. During the surge of patients infected with COVID-19 in the hospital, personnel protective equipment, especially N95 masks, were being conserved for nurses, physicians, and respiratory therapists. Therefore, RDNs were not allowed in the ICU. Virtual ICU rounds were scheduled when time permitted. The RDN recommended the initiation of enteral nasogastric continuous tube feeding, which was initiated on day 1 to maintain the patient's nutrition status.²⁹

The patient tolerated the tube feeding well and was extubated after 5 days on mechanical ventilation. He transferred out of ICU; an oral diet was resumed, and he was later discharged.

IMPROVING HEALTH LITERACY AND USING TEACH-BACK **METHOD**

Health Literacy

The RDN/NDTR team represents the bridge between a therapy that gives a sense of normalcy for individuals' nutrition and the technology-driven health care system. This journey may cause individuals/surrogate/families to accept therapies, such as mechanical ventilation, cardiopulmonary resuscitation, ANH, and other advanced treatments that may not be congruent with their real wishes.²⁸ RDNs can be a part of the interprofessional health care team effort that can facilitate improved health literacy.

Health literacy is the degree to which individuals obtain, process, and understand basic health information and services to make appropriate health decisions. Health literacy involves a range of social, cultural, and individual

factors, and poor health literacy affects all levels of the health care experience, from individuals to providers to health care environments.²⁸

Teach-Back Method

The teach-back technique is an effective method for ensuring that individuals understand the information provided. Individuals either explain or demonstrate what they have learned. If an individual is unable to do this correctly, the information would be retaught using an alternative approach.30 In addition to verbal communication, readability is a significant factor affecting the potential impact of the message. The recommendation is to achieve a fifth-grade reading level or less for informational materials. The identified level as the criterion for low literacy.³¹ Both health literacy and the teachback method of education are useful components for explaining different aspects of nutrition therapies and applying this to advance care planning for individuals.

RECOMMENDATIONS FOR **DEVELOPING POLICIES AND** PROCEDURES TO ACCELERATE PRACTICE CHANGE

Acute Care

Development and implementation of policies and procedures for ethical decision making for enteral and parenteral nutrition in health care facilities require modifications indicative of the specific population, type of health care facility, cultural diversity, and religious affiliation, where applicable. Published recommendations and guidelines from national organizations can be included as a foundation. Implementation of policies and procedures require education for everyone involved in the process. Figure 3 provides a format for an acute care sample policy and procedure. RDNs could use this sample format to expand the crucial considerations section with recommendations and guidelines from the organizations listed and other organizations pertinent to the specific population.²⁶ Also, modification of the procedure section, as required by the collaborative process in the individual institution, would be appropriate.

Long-Term Care Facilities and **Home Care**

State and federal governments regulate long-term care facilities. The Centers for Medicare and Medicaid Services (CMS) includes specific criteria for the use of nasogastric tubes and gastrostomy tubes. F 692 483.25 (g), Assessed ANH states:

Based on a comprehensive assessment, the facility must ensure that (1) A resident who has been able to eat enough alone or with assistance is not fed by enteral methods unless the resident's clinical condition demonstrates that enteral feeding was clinically indicated and consented to by the individual unavoidable; and (2) A resident who is fed by enteral means receives the appropriate treatment and services to restore, if possible, oral eating skills and prevent complications of enteral feeding including but not limited to aspiration pneumonia, diarrhea, vomiting, dehydration, metabolic abnormalities, and nasalpharyngeal ulcers.32

The regulations specify that residents of long-term care facilities have the right to make informed decisions about feeding tube placement, the right to devise an advance directive per state law, and the right to refuse treatment. Facilities are required to inform residents and, if applicable, appropriately authorized resident representative of the risks and benefits of enteral feeding and provide the guidance needed to make an informed decision.

The federal regulations define QOL "as a fundamental principle that applies to all care and services provided to facility residents."³² QOL includes the accomplishment of the individual's goals and control over one's life. Longterm care facilities regulated by CMS are required to employ a qualified dietitian on either a full-time, parttime, or consultant basis to assume the responsibility of the nutritional services.³² The RDN can implement the Academy of Nutrition and Dietetics: Revised 2018 Standards of Practice and Standards of Professional Performance for RDN (Competent, Proficient and Expert) in Post-Acute and Long-Term

Care Nutrition, which provides RDNs with a self-evaluation guide for ensuring competence, identifying knowledge and skills to enhance expertise and advance level of practice in post—acute care and long-term care nutrition.³³

Home health care agencies regulated by the CMS are not required to employ an RDN, but many agencies contract RDN services. Hospice delivers EOL care by professionals who provide medical and spiritual support. Hospice services are provided in multiple settings: the individual's home and in acute or long-term care facilities. The services of the RDN vary with the setting. Figure 4 provides a sample guideline for ANH for a long-term care facility.

RDNs' ROLE IN DESIGNING AND IMPLEMENTING QUALITY IMPROVEMENT PROJECTS

A sample quality improvement project in clinical nutrition ethics could be to identify if there is adequate documentation to determine appropriate involvement by the individual/surrogate/family in the feeding decisionmaking process in the ICU. Other units of the hospital and long-term care facilities could design quality assessment and performance improvement programs, implement them, benchmark them, and share their best practice data with other health care professionals. Data collected could include the presence of advance directives for patients receiving enteral or parenteral nutrition; the individual's age, gender, religion, culture, language; presence of family and surrogate decision maker; family care conferences; palliative care consultations; and bioethics consultations during the hospitalization.³⁴

RDNs could design and lead the project in collaboration with other health care team members. The information from the results would serve as a baseline before implementing new processes, such as development and implementation of a policy and procedure to improve and standardize the communication between the individual/surrogate/family and health care providers on nutrition.³⁴

After implementing the improvement plan, remeasuring would determine the achievement of the targeted goals. Indicators can be measured periodically to assess sustainability. Incorporating a standardized process in clinical ethics and nutrition could then be shared among health care facilities to benchmark best practices and translate ethical decision making into clinical practice.³⁴

ADVANCE CARE PLANNING TOOLS

Numerous resources promote concepts that help individuals and their family better understand advance care planning. Following are resources for health care providers and the public to increase their knowledge in this vital aspect of health care that would be useful when determining the appropriate use of various nutrition interventions accessed in 2020.

- Five Wishes—Aging With Dignity, www.agingwithdignity.org/ five-wishes.php
- National Healthcare Decisions Day, www.nhdd.org
- Physician Orders for Life-Sustaining Treatment, www. polst.org
- The Conversation Project, www. theconversationproject.org

Advance care planning timing is especially crucial for individuals diagnosed with dementia. Recommendations for advance care planning practice for dementia include the following: (1) discussions early in the diagnosis of dementia, while the patient still has decisional capacity; (2) clinician competencies required on communication and expert knowledge of dementia; (3) case management approach in supporting families; (4) shared decision making within the and (5) clinician-specific family; training.35

CONCLUSION

RDNs work collaboratively as part of an interprofessional health care team to make recommendations on oral feeding, including providing, withdrawing, or withholding ANH, and should serve as active members of bioethics committees. The process of ethical deliberation includes applying concepts dealing with cultural values and religious diversity necessary to integrate clinical ethics into nutrition care. Incorporating screening for QOL

goals is essential before implementing the NCP and improving health literacy with individual interactions. Developing institution-specific policies and procedures is necessary to clarify the issues regarding ANH, clinical ethics, and devising quality improvement projects to determine best practices.

References

- Code of Ethics for the Nutrition and Dietetics Profession. Academy Board of Directors and the Commission on Dietetic Registration Board. Effective June 1, 2018, https://www.eatrightpro.org/-/media/ eatrightpro-files/career/code-of-ethics/ coeforthenutritionanddieteticsprofession. pdf. Accessed February 28, 2020.
- Schwartz DB. Ethics in Action column: Applying dietetics practitioner's code of ethics to ethical decisions for withholding/withdrawing medically assisted nutrition and hydration. J Acad Nutr Diet. 2015;115:440-443.
- 3. Patient Self Determination Act of 1990 H. R.4449. 101st Congress (1989-1990). https://www.congress.gov/bill/101st-congress/house-bill/4449. Accessed February 28, 2020
- **4.** Druml C, Ballmer PE, Druml W, et al. ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clin Nutr.* 2016;35:545-556.
- 5. Schwartz DB, Pavic-Zabinski K, Tull K. Role of a nutrition support clinician on a hospital bioethics committee. *Nutr Clin Pract*. 2019;34(6):869-880.
- Schwartz DB, Barrocas A. Ethics and law. In: Mueller C, Lord LM, Marian M, McClave SA, Miller S, eds. The ASPEN Adult Nutrition Support Core Curriculum. 3rd ed. Silver Spring, MD: American Society for Parenteral and Enteral Nutrition; 2017: 785-804.
- Schultz MAF. Helping patients and families make choices about nutrition and hydration at the end-of-life. Medscape. medscape.com/viewarticle/703907. Published June 4, 2009. Accessed March 28, 2020
- Casarett D, Kapo J, Caplan A. Appropriate use of artificial nutrition and hydrationfundamental principles and recommendations. N Eng J Med. 2005;353(24):2607-2612.
- Boullata J, Carney LN, Guenter P. A.S.P.E.N. Enteral Nutrition Handbook. Silver Springs, MD: American Society for Parenteral and Enteral Nutrition; 2010:75-77.
- Brantley SL, Russell MK, Mogensen KM, et al. American Society for Parenteral and Enteral Nutrition and Academy of Nutrition and Dietetics. Revised 2014 Standards of Practice and Standards of Professional Performance for Registered Dietitian Nutritionists (Competent, Proficient, and Expert) in Nutrition Support. Nutr Clin Pract. 2014;29(6):792-828.
- Ukleja A, Gilbert K, Mogensen KM, et al. Standards for nutrition support: adult hospitalized patients. J Parenter Enter Nutr. 2018;33(6):906-920.

- 12. A.S.P.E.N. Ethics Position Paper Task ForceBarrocas A, Geppert C, Durfee SM, et al. A.S.P.E.N. ethics position paper. *Nutr Clin Pract.* 2010;25(6):672-679.
- 13. Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev.* 2009;2:CD007209.
- 14. Schwartz DB. Enteral nutrition and dementia integrating ethics. *Nutr Clin Pract*, 2018;33:377-387.
- American Geriatrics Society feeding tubes in advanced dementia position statement. [Am Geriatr Soc. 2014;62(8):1590-1593.
- Ijaopo EO, Ijaopo R. Tube feeding in individuals with advanced dementia: A review of its burdens and perceived benefits. J Aging Res. 2019;2019:7272067.
- Schwartz DB, Barrocas A, Wesley JR, et al. A.S.P.E.N. special report: Gastrostomy tube placement in patients with advanced dementia or near end of life. Nutr Clin Pract. 2014;29:829-840.
- 18. Giacino JT, Katz DI, Schiff ND, et al. Practice guideline update recommendations summary: Disorders of consciousness: Report of the Guideline Development, Dissemination, and Implementation Subcommittee of the American Academy of Neurology; the American Congress of Rehabilitation Medicine; and the National Institute on Disability, Independent Living, and Rehabilitation Research. Neurology. 2018;91(10):450-460.
- American Society for Parenteral and Enteral Nutrition Board of Directors. American Society for Parenteral and Enteral Nutrition statement on ethics of withholding and/or withdrawing nutrition support therapy. Nutr Clin Pract. 2008:23:579.
- **20.** Mirhosseini N, Fainsinger RL, Baracos V. Parenteral nutrition in advanced cancer:

- indications and clinical practice guidelines. *J Palliat Med.* 2005;8(5):914-918.
- Raijmakers NJH, van Zuylen L, Costantini M, et al. Artificial nutrition and hydration in the last week of life in cancer patients. A systematic literature review of practices and effects. Ann Oncol. 2011;22(7):1478-1486.
- Barrocas A, Schwartz DB, Seres DS, Hasse JM, Mueller CM. Ethical framework for nutrition support resource allocation during shortages: Lessons from COVID-19. Nutr Clin Pract. 2020;35(4):599-605.
- Emanuel EJ, Persad G, Upshur R, et al. Fair allocation of scarce medical resources in the time of Covid-19. N Engl J Med. 2020:382:2049-2055.
- **24.** Steinberg S. Cultural and religious aspects of palliative care. *Int J Crit Illn Inj Sci.* 2011;1(2):154-156.
- 25. Netuveli G, Blane D. Quality of life in older ages. *Br Med Bull*. 2008;85:113-126.
- 26. Geppert CMA, Barrocas A, Schwartz DB. Ethics and law. In: Mueller C, McClave S, Schwartz DB, Kovacevich D, Miller S, eds. The A.S.P.E.N. Adult Nutrition Support Core Curriculum. 2nd ed. Springfield, MD: American Society for Parenteral and Enteral Nutrition; 2012:656-676.
- Barry MJ, Edgman-Levitan S. Shared decision making—the pinnacle of patient-centered care. N Engl J Med. 2012;366(8):780-781.
- Reuben DB, Tinetti ME. Goal-oriented patient care—an alternative health outcomes paradigm. N Engl J Med. 2012;366(8):777-779.
- ASPEN-SCCM. Nutrition therapy in the patient with COVID-19 disease requiring ICU care. https://www.nutritioncare.org/uploadedFiles/Documents/Guidelines_and_Clinical_Resources/Nutrition%20Therapy%

- 20COVID-19_SCCM-ASPEN.pdf. Updated April 1, 2020. Accessed April 1, 2020.
- **30.** Carbone ET, Zoellner JM. Nutrition and health literacy: A systematic review to inform nutrition research and practice. *J Acad Nutr Diet*. 2012;112(2):254-265.
- 31. Weiss BD. Health Literacy and Patient Safety: Help Patients Understand Manual for Clinicians. 2nd ed. American Medical Association. http://www.partnershiphp.org/Providers/Health%20Feducation/CandLToolKit/2%20Manual%20for%20Clinicians.pdf. Accessed September 9, 2020.
- 32. US Department of Health and Human Services, Centers for Medicare & Medicaid Services. CMS Manual System: State Operations Manual. Appendix PP—Guidance to surveyors for long term care facilities. https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap_pp_guidelines_ltcf.pdf. Accessed March 7, 2020.
- Robinson G, Cryst S. Academy of Nutrition and Dietetics: Revised 2018 Standards of Practice and Standards of Professional Performance for Registered Dietitian Nutritionists (Competent, Proficient, and Expert) in Post—Acute Care and Long Term Care Nutrition. J Acad Nutr Dietetics. 2018;118(9):1147-1780. e25.
- 34. Schwartz DB. Ethical and legal issues in gastrointestinal nutrition interventions. In: Matarese LE, Mullin G, Raymond J, eds. *The Health Professional's Guide to Gastrointestinal Nutrition*. Chicago, IL: AND; 2014:333-344.
- 35. Dening KH, Sampson EL, De Vries K. Advance care planning in dementia: recommendations for healthcare professionals. *Palliat Care*. 2019;12. 1178224219826579.

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